

Experiences of Individuals Awaiting Lung Transplantation

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Summary

Lung transplantation is an established intervention for patients with advanced and life-threatening respiratory disease. Unfortunately, the shortage of organ donors results in a need for organs that greatly exceeds availability. This narrative review aimed to investigate the experiences of patients with respiratory diseases who wait for lung transplantation. Articles were retrieved from medical literature databases. Thirteen qualitative studies were reviewed, one of them used a mixed method. We found that individuals faced varied and complex situations differently while waiting for lung transplantations, depending on physical, psychological, social, and existential factors. Waiting gives hope for a future without the limitations imposed by the disease but also causes great stress. Many individuals struggled with the existential guilt associated with the privilege of having access to transplantation. This review highlighted that support from health-care professionals, next of kin, patients who had previously received a transplantation, and close friends have a vital role to play for individuals waiting for a lung transplantation. Key words: respiratory diseases; lung transplantation; waiting list; experiences; palliative care. [Respir Care 2018;63(12):1535–1540. © 2018 Daedalus Enterprises]

Introduction

Respiratory diseases impose enormous health burdens worldwide, not least disability and early death.^{1,2} Even

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though survival is prolonged with today's better management, the incidence of disease is increasing. According to the World Health Organization, COPD is the most common respiratory disease globally. This disease represents a growing problem in the world and is the second most common respiratory disease in the United States^{3,4} Other worldwide severe respiratory diseases are cystic fibrosis

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Table 1. Statistics of the Number of Patients on the Waiting List at Year End 2016; Transplanted, Deceased, and on the Waiting List at Year End 2017

Database	Patients on the Waiting List at Year End 2016	Lung Transplantation Recipients in 2017	Deceased on the Waiting List at Year End 2017	Patients on the Waiting List at Year End 2017
Organ Procurement and Transplantation Network (United States)*	1,430	2,553	176	1,368
Eurotransplant (8 countries in Europe)†	797	641	105	817
Scandiatransplant (Scandinavia and Estonia)‡	144	161	22	122

Overview of the number of people waiting for lung transplantation, transplanted, deceased, and on the waiting list at year end 2017 in countries registered with the Organ Procurement and Transplantation Network, Eurotransplant, and Scandiatransplant.

* <https://Optn.Transplant.Hrsa.gov/data/view-data-reports/national-data>. Accessed January 4, 2018.

† <http://Statistics.Eurotransplant.org>. Accessed January 4, 2018.

‡ <http://www.Scandiatransplant.org/data>. Accessed January 4, 2018.

and interstitial lung disease.⁵⁻⁸ Some diseases are congenital, such as cystic fibrosis, whereas others can be acquired through smoking, such as COPD.^{9,10}

Lung transplantation is an established intervention for patients with advanced and life-threatening respiratory disease for which standard medical treatment is no longer effective or for which there is no effective standard medical treatment.¹¹ Three diseases that often necessitate lung transplantation are COPD, interstitial lung disease, and cystic fibrosis.^{12,13} COPD is the leading indication for lung transplantation worldwide and the second indication in the United States.⁴ The indication for lung transplantation is profound reduction in lung function and an expected survival of <2 years.^{12,14,15} In addition, worsening quality of life due to the disease can also indicate a need for lung transplantation.^{11,12,16-19}

Before proceeding to a transplantation workup, the patient must meet certain criteria. Contraindications for transplantation include a lack of treatment adherence; malignancy; malnutrition; heart, kidney, and/or liver failure; untreated psychiatric illness; deformity of the chest wall; and lack of social support.^{11,13,20} In essence, being listed for lung transplantation means a chance to survive.¹¹ However, there is a shortage of organ donors globally, and the need for organs greatly exceeds the availability.^{13,21-23} This results in long waiting times, and, in many cases, the patient dies before an organ becomes available, either as a result of complications of the underlying illness or because they become too weak to survive a transplantation (Table 1).^{20,24}

One dilemma faced by individuals with severely reduced lung function who are waiting for a lung transplantation is that they rarely receive palliative care. Results of studies show that treatment-oriented care provided for patients to sustain a lung transplantation is often prioritized.²⁵⁻²⁷ Thus, a patient waiting for a lung transplantation risks dying without having received palliative care or having discussed what he or she wants at the end of life.^{26,28}

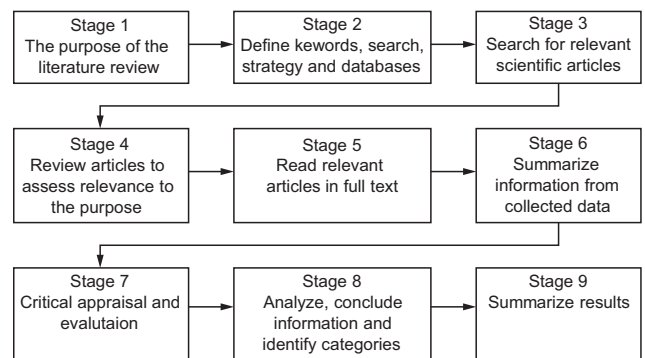


Fig. 1. Literature review model. From Reference 31.

In many cases, palliative care is only offered when a transplantation has been ruled out and the patient has only a few weeks to live.^{20,29,30} If we are to understand how best to provide this type of care, we need to understand these patients' experiences while waiting for a lung transplantation. Thus, this narrative review aimed to investigate the experiences of patients with respiratory diseases while they waited for a lung transplantation.

Criteria for Selecting Studies

We analyzed and synthesized original scientific articles of study subjects' subjective experiences of waiting for a lung transplantation. We followed the literature review model described by Polit and Beck³¹ (Fig. 1).

Search Process

Stage 1. In accordance with the model of the literature review process³¹ the first step is to establish the aim of the review; in this case to describe patients' subjective experiences while waiting for lung transplantation.

Stage 2. In accordance with the model, key words, search strategies, databases, and inclusion and exclusion criteria

were selected. Search strategies and databases were decided in consultation with a librarian, and the following 3 electronic databases were selected; PubMed, PsycINFO, and CINAHL. To ensure good-quality articles, the search strategy used the following inclusion criteria: (1) English language; (2) published in full text, after 2002; (3) qualitative and/or mixed method; (4) peer reviewed; (5) approved by an ethics review committee; and (6) covered experiences or conceptualization of waiting for a lung transplantation.³² Case reports and articles that studied this issue from a family's or relative's or health-care professionals' perspectives were excluded. The age of the study subjects was not an exclusion criterion. To achieve broad and relevant searches, all the searches in the databases used both database-specific topics and free text. Key words were used and combined in different variations by using Boolean operators ("and" and "or") (see the supplementary materials at <http://www.rcjournal.com>).^{31,32}

Stage 3. The searches resulted in a total of 2,525 articles (first selection). These potentially relevant articles were distributed in the various databases as follows: PubMed (2,345), PsycINFO (91), and CINAHL (89). Subsequently, their titles and abstracts were screened, which resulted in the exclusion of 2,415 articles because they did not match the inclusion criteria. The remaining articles formed the initial sample.

Stage 4. From this initial sample, 110 abstracts were reviewed. Of these articles, 87 were subsequently excluded due to duplication, quantitative design, the perspective was that of the family or relative or health-care professionals and not that of the patient, the abstract did not match the aim of the review, or because they included diagnoses other than respiratory diseases.

Stages 5 and 6. In the second sample, 23 relevant articles were reviewed and read in full text by one author (US). After reading, a summary, short sentences, codes, and key words were recorded. This method facilitated review of the content and acted as a guide for the final analysis phase. Ten articles were excluded after this review because their objectives did not correspond to the aim of this review (Fig. 2).

Data Analysis

Stage 7. A critical quality review was performed according to Polit and Beck.³¹ By using a review template, one author (US) critically reviewed and evaluated all the remaining articles in accordance with a qualitative study review as described by Willman et al.³² Article validation provides a measure of the scientific quality of a study and its ability to answer a particular question reliably, which results in an increased body of evidence.³² All the items were scored in accordance with a review template in which "yes" received 1 point, and "no" and "do not know" re-

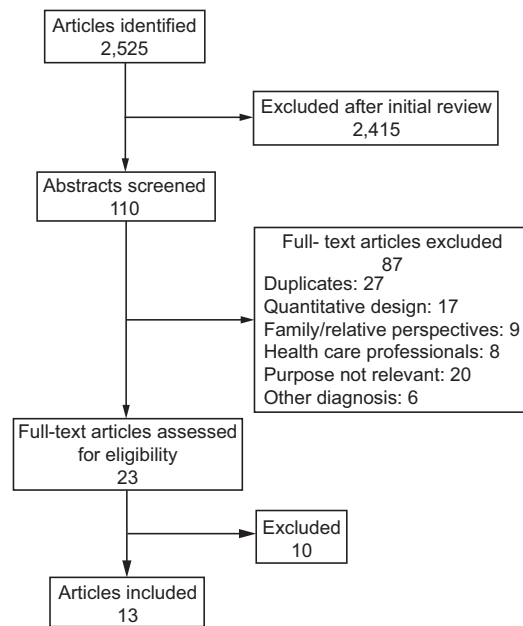


Fig. 2. Flow chart.

ceived 0 points. If $>70\%$ of the questions were answered with "yes," then the article was rated as medium quality, whereas articles that scored $\geq 80\%$ were rated as high quality. Six articles thus were deemed to be of high quality, and 7 articles were of medium quality (see the supplementary materials at <http://www.rcjournal.com>).

Stage 8. This step involves the analysis phase. All data were categorized and compiled. Key words and sentences important for the purpose were marked and encoded in different colors. The first author (US) coded the findings from the primary studies, conceptualized the data, and inductively categorized concepts that pertained to patients' experiences of waiting for lung transplantation (Table 1).

Stage 9. The final step in the model is to make a condensed summary of the results.³¹ After analysis by 2 authors (US, TG), 3 main categories were identified.

Review of the Literature

The results of this narrative review were based on 13 articles: 12 using a qualitative method and 1 using a mixed method (see the supplementary materials at <http://www.rcjournal.com>). The studies were conducted in Sweden (3), the United Kingdom (3), Australia (2), Switzerland (2), Canada (1), Germany (1), and the United States (1). The subjects were between ages 15 and 68 y (mean age, 49 y).

Challenges for Subjects

The subjects often felt disappointment and frustration in anticipation of the lung transplantation.³³⁻³⁵ They also de-

scribed feelings of insecurity and low mood.³³⁻⁴¹ Activities previously taken for granted, which formed part of the subject's identity, became impossible to carry out and difficult to substitute. The subjects lacked both physical and mental energy. Some described a labile mood with an altered perception of themselves, their surroundings, and their future. The subjects almost completely lost the ability to feel joy.^{33,37,38,42} Depression, anxiety, and stress were experienced when the subjects were temporarily placed on hold status on the transplantation waiting list. This occurred when they had an infection or when a decline in respiratory function stabilized. The subjects became aware that lung transplantation was the only option to survive, and many described a fear of dying, which resulted in anxiety and depression.^{33,35,36,38,39,42-44}

While waiting for lung transplantation, many subjects experienced concern and fear for the future. The subjects were worried about being unable to control their situation.^{34,35,38,39,42} Some subjects described that it was hard to cope with a feeling of total loneliness.^{36,39} For other subjects faith and trust in God helped them to cope with an uncertain future.^{34,35,40,41} Others described finding inner peace by surrendering their lives to God. This symbolized power and strength for them.^{39,42,43} Many subjects also struggled with feelings of guilt that were difficult to handle. They experienced guilt when given a place in the queue because others in need of a lung transplantation would not have the same chance. They could also feel guilty about the organ donor, because the donation is the result of someone dying. So, they grieved the fate of the donor as well as being concerned about the grief of the donor's relatives.^{39,45} Moreover, the subjects felt bad about what they put their own families through. They saw themselves as an economic burden on their family,^{34,37-39,43,45} and regretted their inability to help with household chores and other practical work at home.^{34,37,39,44}

Sense of Security

Waiting for a lung transplantation created a sense of meaning for many subjects through hope, excitement, and confidence in the future.^{35-37,39,42} A desire to experience freedom, to be independent of others, and to manage breath without oxygen gave subjects a meaningful goal to fight for.^{33-37,39-41,43,45} The subjects reported a sense of security before surgery when told about other patients who had successfully received a transplantation.^{34,42} Other subjects described not only security but also gratitude at living in a country where transplantation is routinely performed and described high confidence in the medical teams who work with them.⁴⁴ Organ donation was sometimes described as a gift that offers a continuing life of better quality.^{37,44}

Support and information from health professionals were described as important while waiting for lung transplan-

tation.^{33,34,37-42,44} The waiting time involved frequent visits to the transplantation unit where many subjects experienced friendly, unforced contact with the health-care professionals.^{33,35,38,40,44} Nursing support, empathy, positive thinking, and humor were perceived positively, and the opportunity to come into contact with the health-care staff at any time created a feeling of safety.^{34,40,41} Having the opportunity to meet other patients who have undergone a transplantation and to exchange experiences was often appreciated by subjects who were waiting for lung transplantation and made them feel hopeful for the future.^{34,38,42} Support, comfort, encouragement, and involvement from close relatives were also considered by most subjects to provide strength and energy.^{33,34,37-39,42,44} Some subjects had problems with memory during the waiting period, which affected them negatively. Subjects described difficulty taking in all of the information and appreciated that it was provided repeatedly.^{33,34,40,41}

Limitations in Daily Life

Subjects waiting for a lung transplantation were often housebound and expressed frustration about not being able to travel as they wished or having to isolate themselves to avoid infections.^{35,36,39,44,45} The complex practicalities and the fear of infections meant that the subjects mostly socialized with friends via the internet and telephone rather than in person.^{33,36} Another limitation was that they always had to be ready for the transplantation. It could be very stressful waiting for the telephone call that they were anticipating so eagerly. They were afraid that they would miss the call about their potential transplantation and, therefore, felt unable to fully engage in other activities. These factors meant that they often withdrew socially.^{33,35,39,43,44}

Inhalation therapy and physical activity were often described as stressful and meaningless.^{36,38,39} At the same time, they understood the importance of being in optimal physical condition to cope with the potential lung transplantation. During physical activity and inhalation therapy, many subjects described that they could very easily imagine how new healthy lungs could feel, when every step and breath would not limit everyday activities.³⁶⁻⁴¹

Summary

Waiting for a lung transplantation is a complex situation. For many subjects the waiting list offered hope for a better survival outcome and expectation for normality without the limitations imposed by the disease. However, many subjects also experienced physical, psychological, and social obstacles and limitations in their daily life during this waiting period. Many subjects struggled with existential guilt associated with the privilege of having access to transplantation and their dependence on others. The treatment

of subjects with cystic fibrosis and other patients with respiratory disease who were awaiting lung transplantation is highly challenging, therefore, palliative care is inherently complex.

These patients lie in the balance between successful transplantation or dying before a donor's lungs become available. It is no surprise, then, that there has long been practical tension between the cystic fibrosis medical care team and the palliative care team, the so-called "either/or approach"^{2,21,29,46,47} In an either/or approach, the patient with end-stage cystic fibrosis listed for lung transplantation is *either* treated with active life-prolonging medical care, such as lung transplantation, *or* with palliative care that is often introduced abruptly in the last days of life. The focus, however, has predominantly been on providing medical care.^{29,46} Because of this focus, discussion about initiating palliative care is often delayed until patients are too sick to participate in the conversation.^{17,27} For many patients and their families, recognizing that they have reached the end of their life can come as a shock.⁴⁸

If, and when, palliative care should be discussed has been reviewed in a number of studies in terms of the timing of the discussions, the difficulties surrounding palliative care discussions,^{38,44} and appointing the most appropriate person in the medical team to initiate conversations regarding palliative care.³⁴ Goggin and Cohen⁴⁶ emphasize that health-care professionals do not always have sufficient knowledge of palliative care and, therefore, that they are unsure of how they should talk to patients about the end of life. Early integration of palliative care improves the quality of life of the patient and enhances palliative care, but the optimal timing and effective model for integrating palliative care for patients awaiting lung transplantation remain uncertain.^{49,50}

Based on our findings, subjects struggled with psychological, existential, social, and physical challenges while waiting for lung transplantation. Still, palliative care was often introduced late or not at all. For those challenges to be met, end-of-life decision-making with patients and their families should be addressed earlier. To support this, basic skills and competencies in end-of-life conversations should ideally be further developed as part of the health-care education curriculum. In addition, communication training workshops for health-care professionals could be a tool because they have a difficult and stressful task to simultaneously provide hope and palliative care to patients with life-threatening respiratory diseases.

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